Effects in the Military of Brain Injury on Families & Caregivers

NAVY AND MARINE CORPS COMBAT & OPERATIONAL STRESS CONFERENCE 2010:
"TAKING ACTION, MEASURING RESULTS"

NAVAL CENTER
COSC
COMBAT & OPERATIONAL STRESS CONTROL

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I. What Changes after Head Injury?

II. Relationship Changes

III. Effects on Caregivers (coping cognitive burden)

IV. Research on Family Needs Post-TBI

V. Implications for Interventions

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

II. Relationship Changes

III. Effects on Caregivers (coping cognitive burden)

IV. Research on Family Needs Post-TBI

V. Implications for Interventions

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I.

II. Relationship Changes

III. Effects on Caregivers (coping cognitive burden)

IV. Research on Family Needs Post-TBI

V. Implications for Interventions

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I.

II. Relationship Changes

III. Effects on Caregivers (Coping & Cognitive Burden)

IV. Research on Family Needs Post-TBI

V. Implications for Interventions

NAVAL CENTER COSC COMBAT & OPERATIONAL STRESS CONTROL

II. Relationship Changes

III. Effects on Caregivers (coping cognitive burden)

IV. Research on Family Needs Post-TBI

V. Implications for Interventions

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I. What changes after TBI?

- **Improved survival rates >>>**
- **The double-edged sword of rehabilitative reality**
- **Shared responsibility becomes primary responsibility**
- **Community reintegration runs a far distant second place**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I. What changes after TBI?

- Improved survival rates
- **The double-edged sword of rehabilitative reality**
- Shared responsibility becomes primary responsibility
- Community reintegration runs a far distant second place

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I. What changes after TBI?

- Improved survival rates
- The double-edged sword of rehabilitative reality
- **Shared responsibility becomes primary responsibility**
- Community reintegration runs a far distant second place

NAVAL CENTER COSC COMBAT & OPERATIONAL STRESS CONTROL

I. What changes after TBI?

- Improved survival rates
- The double-edged sword of rehabilitative reality
- Shared responsibility becomes primary responsibility
- **Community reintegration runs a far distant second place**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

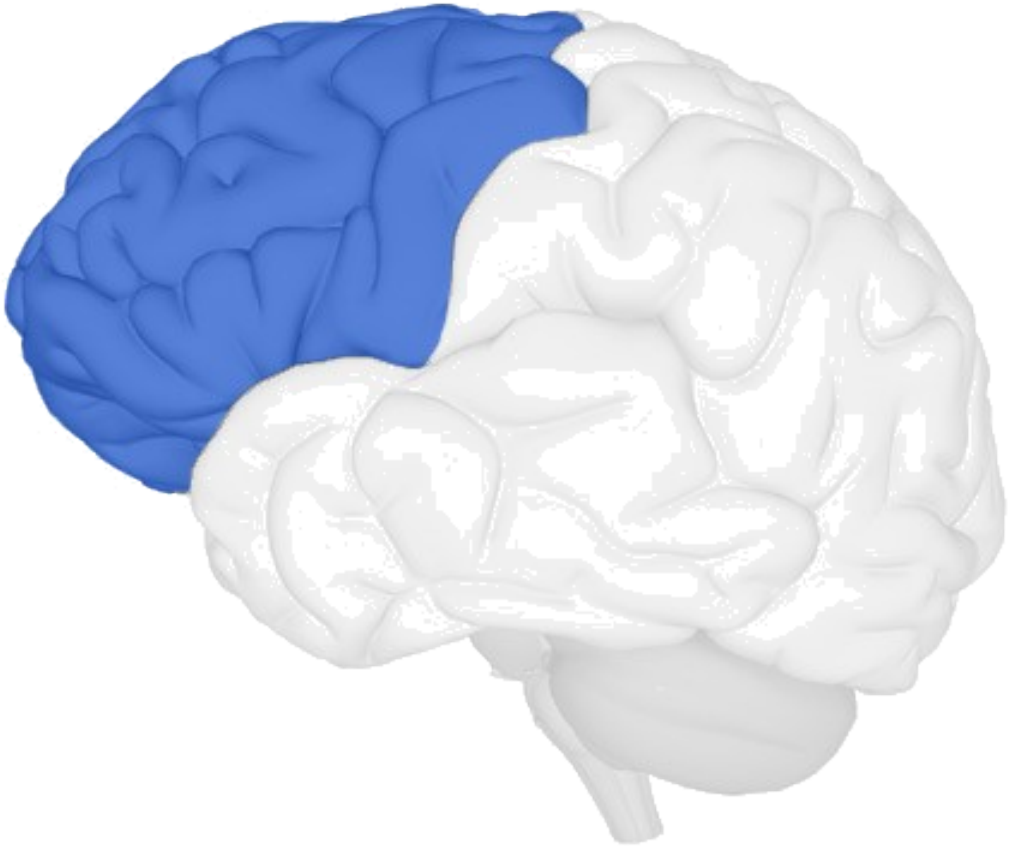
I. What changes after TBI?

Patient personality changes >>>

- Family burden greater in TBI than ortho

- Nearly twice the rate of family dysfunction (Wade et al., 1998)

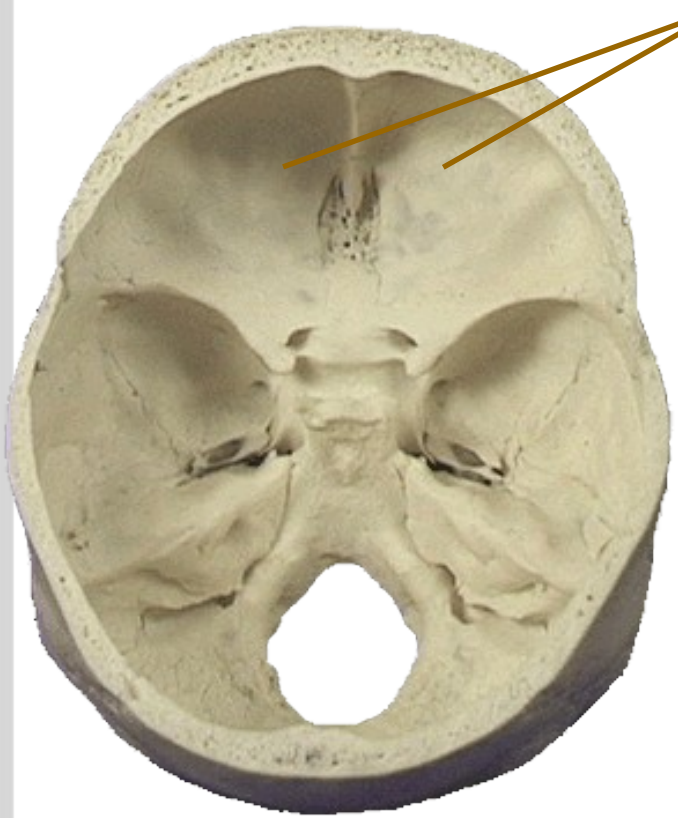
Frontal Lobe

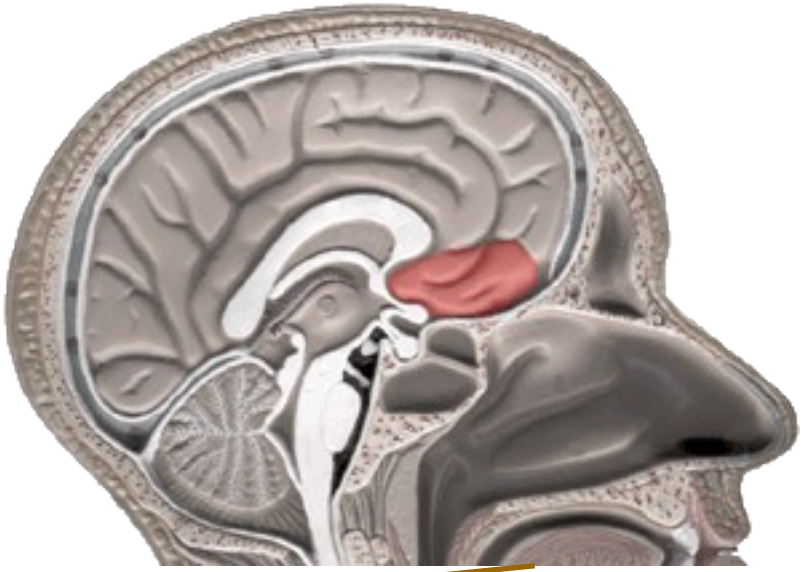


The frontal lobe is the area of the brain responsible for higher cognitive functions.

These include:

- **Problem solving**
- **Spontaneity**
- **Memory**
- **Language**
- **Motivation**
- **Judgment**
- **Impulse control**
- **Social and sexual behavior.**





NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

I. What changes after TBI?

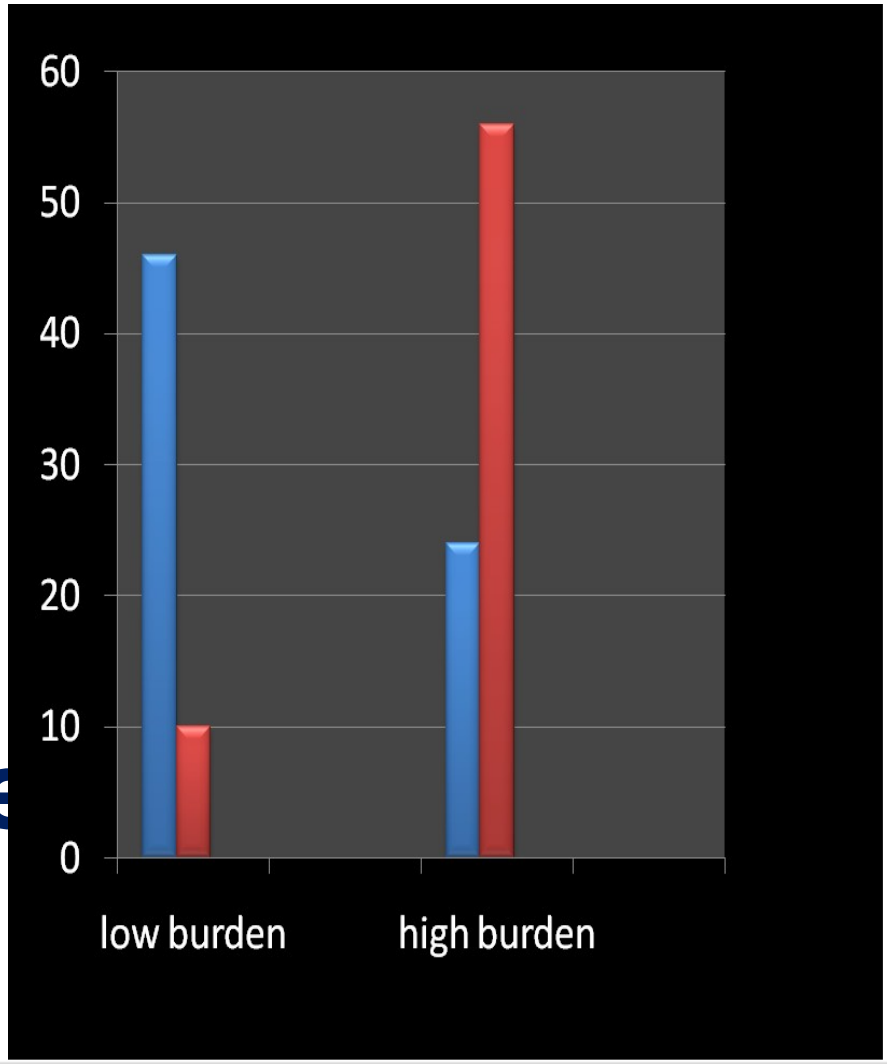
- Patient personality changes

- **Family burden greater in TBI than ortho**

- **Nearly twice the rate of family dysfunction (Wade et al., 1998)**

II. Relationship Changes

- Caregiver's emotional cornucopia
- "Chronic pall on their lives" (Lezak, 1978)
- Chronic effects of caregiver burden (Brooks et all, 1986)



Cognitive Burde
at 5 years post injury
(Brooks et al. 1986)

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

II. Relationship Changes

- **FAMILIES:**
- > 1/3 impacted at “moderate level”
- 30% - lessened $; approx 3/8 housing change
- 16% a worsening of adult relationships in the family (Montgomery et al, 2003)

NAVAL CENTER COSC COMBAT & OPERATIONAL STRESS CONTROL

II. Relationship Changes

- **PEERS/ SIBLINGS:**
  - **2/3 siblings were adversely effected** (Montegomery et al, 2002)
  - **More so in TBI than ortho (Swift et al, 2003)**
  - **Gender differences in its expression (Perlesz, 2000)**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

II. Relationship Changes

- **PARENTS & SPOUSES:**
- Veteran spouses > in “the “man’s role” and < in child care
- “don’t have a husband”
- 1/5 threatened with physical violence

Ill Effects on Caregiving

Long Term Family Functioning 3.5 yrs post-TBI (Douglas & Spellacy, 1996)

- Variables :
  - demographics
  - Injury-related
  - Patient- related
  - Caregiver Variables

III. Effects on Caregivers

- Long Term Family Functioning 3.5 yrs post-TBI (Douglas & Spellacy, 1996)

- largest variance (55%) accounted for by caregiver depression & social support

- Stress, anxiety, burden &

III. Effects on Caregivers

Primary Caregivers Psychological Status in Family Functioning After TBI (Kruetzer et. al 1994)

- Measures: BSI & FAD

- Results: 50% elevated stress, 33% anxiety, 25% depression, elevations on Paranoia & psychoticism (Burden & alienation)

III. Effects on Caregivers

(Wells et al, 2005)

- lack of empathy
- Memory disturbance?
- Impaired impulse control
- Neuropsychological predictions?

III. Coping Responses

- Denial in acute phase
  - Common Fantasies
  - Verbal Refusal
  - Inappropriate Responses (Romano)
- medication use
- Acceptance yields better functioning

III. Coping Responses

- **Acute Impact of TBI on Family Structure and Coping Responses (Curtiss et al, 2000)**

- **Examined changes in family structure post-TBI**

- **Questionnaires 6 month pre and**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

III. Coping Responses

- Cohesion & Adaptability
- Balanced & Extreme families
- Who adapts the best?

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

III. Coping Responses

- **Participants:**

  Spouses of 21 active duty military with non-penetrating TBI (DVBIP pts)

- **Measures:**
  - Faces II (30 Likert responses)
  - Coping Response Inventory (58 Likert)

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

III. Coping Responses

Results:

Significant family change in coping
(relative to coping of prior stressors)

Balanced families changed the most (70%)

At 1 yr, they were still functioning the best

III. Coping Responses

- **Balanced:** used similar coping but reduced emotion & reward behavior…may need supportive tx to allow painful affect and acknowledgement of loss

- **Diffs in family structure** coping may help tailor diff needs and tx responses

IV. Research on Family Needs Post-TBI

- **Predicting Family Needs After Brain Injury: Implications for Intervention (Serio et al 1995)**

- **N = 180; spouses (43%) parents (36%)**

Scale	Met Needs	Unmet	Diff
Medical Info	63	14	49
Emotional Support	42	30	12
Instrumental Support	47	19	28
Professional Support	46	26	20
Support Network	52	41	11
Total	55	19	46

Results/Discussion (SERIO ET AL, 1995)

- Different needs for caregivers
- Spouses with more caring time had fewer needs met (nonsignificant for parents)
- Negative relationship between pts problems and needs met (> = <)
- Neuropsychological testing not

- **Outcome predictors vary**
- **Relatives rating are a good predictor (over more likely thought variables)**
- **Time since injury and LOC were not strong predictors**
- **Numerous variables must be considered including coping style, motivation, pre-injury factors**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

IV. Research on Family Needs Post-TBI

- Resource info, future care, effects of injury Campbell, 1988
- Clear explanations, realistic expectations, emotional support Mauss & Ryan, 1981
- Honesty, close communication, medical information Mathias (1984) in Kreutzer

NAVAL CENTER COSC COMBAT & OPERATIONAL STRESS CONTROL

IV. Research on Family Needs Post-TBI

- **Family Needs After Brain Injury (Kreutzer et al, 1994)**
- **Method**
- **Instruments**

NAVAL CENTER COSC COMBAT & OPERATIONAL STRESS CONTROL

IV. Research on Family Needs Post-TBI

RESULTS:

Similar findings in terms of needs wanted BUT….want didn't they perceive they needed?

Table 3: 10 Needs Most Frequently Rated as *Not Important*

- To have help keeping the house 32%
- To be reassured that it is usual to have strong negative feelings about the patient 19%
- To have help from other members in taking care of the patient 19%
- To give my opinions daily to others involved in patient's care, rehab or education 18%
- To spend time with my friends 18%

- **To have my spouse understand how difficult it is for me 16%**
- **To have other family members understand how difficult it is for me 15%**
- **To be encouraged to ask others to help me 15%**
- **To discuss my feelings about the patient with someone who has gone through the same experience 15%**
- **To have help getting over my doubts and fears about the future 13%**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

IV. Research on Family Needs Post-TBI

The highest 10 ranked endorsed by less than 20%....individual differences !

- Was a greater set of needs for those caregivers of male patients

IV. Research on Family M

INFORMATION UNCERTAINTIES

IV. Research on Family Needs Post-TBI

- **RELATIONSHIPS**
  - **Between the pt and the team**
  - **Family members and the team**
  - **Relationships within the team**

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

QUALITATIVE STATEMENTS
INFORMATION

Patient: *"She is awkward, she didn't know how to tell me"*.

Family member: *"We didn't get much information, we had to ask them for more".*

Physician: *"You don't want to give the family too big a blow, it's a big pill to swallow"*

- **UNCERTAINTY**
- Patient: *"I had the feeling they were hiding something from me".*
- Family member: *"They want to protect themselves… the more they say the more they leave themselves open to making a mistake… the less you say the better".*
- Physician: *"You can't help them about the uncertainty because we share the same doubts".*

- **INDIVIDUAL CARE-TEAM RELATIONSHIP**

- Professional: *"You're a cardiologist, you are the heart, for another one, you are the foot, for another one you the brain. It is a time when the patient is treated as an object".*

- Physician: *"They get the impression that we are controlling them, that we don't have confidence in them"*

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

FAMILY CARE-TEAM RELATIONSHIP

- Family Member: *"In intensive care, I found that all the energy was directed at the patients, and that's understandable. But you feel brushed aside".*

- Family Member: *"we were told " we need the relatives" but I had the feeling they weren't listening to me"*

V. Implications for Ongoing Interventions

- preventing (a priori) and putting out family "fires"

- Assessing which factors are relevant…
  - At what time
  - With what family member
  - To what extent

NAVAL CENTER COSC
COMBAT & OPERATIONAL STRESS CONTROL

V. Implications for Ongoing Interventions

Encourage and enable social contacts

Social self report measure

Relatives should be encouraged to utilize other resources including advocacy groups, peer support groups and day treatment planning.

I thank you for your time and for the services you provide to our men and women in the military.